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**Testimony of the Connecticut Children's Medical Center
to the Insurance and Real Estate Committee regarding
Senate Bill 200 An Act Expanding Health Insurance Coverage for Specialized Formula
March 6, 2014**

Senator Crisco, Representative Megna, members of the Insurance and Real Estate Committee, thank you for the opportunity to share my thoughts about *Senate Bill 200 An Act Expanding Health Insurance Coverage for Specialized Formula*. My name is Melanie Sue Collins, MD, and I am the associate director of the Central Connecticut Cystic Fibrosis Center and a pediatric pulmonologist at the Connecticut Children's Medical Center and I am submitting this testimony in support of the proposed bill.

Optimal growth is critical for all children, however, for children with cystic fibrosis (CF) it is life-altering. Numerous studies have demonstrated that maintaining at body-mass index (BMI) at or above the 50th percentile is associated with improved pulmonary function outcomes and better quality of life. The BMI data of our center's CF patients' is a nationally monitored metric by the CF Foundation.

Patients with CF have 1.5-2x the calorie needs of people without CF. For this reason, our patients may need supplemental formulas to get the amount of calories required to achieve normal growth and development. While the proposed changes affect only those individuals aged 12-26, this can be a critical period of growth and development. Many young people with CF aged 12-26 start to lose weight while going thru the rapid changes of puberty into young adulthood. Use of supplemental formula during this stage is critical to promoting normal growth and improved pulmonary outcomes.

When you work with children and families with CF, you begin to realize that we ask a great deal of them between hours of treatments, a constant focus on aggressive nutritional therapy and the family stress of having a child with a chronic, life limiting disease. To help our patients realize the importance of nutrition, we have a little chant: "the more weight you gain, the taller you grow and the taller you grow the bigger your lungs are and the bigger your lungs are the less you have lose."

Normal adults don't start to lose lung function until age 27, please help us support the optimal lung function of our patients with CF by accepting the proposed changes to Senate Bill 200 and continue life-saving formula supplementation through age 26. Thank you for your consideration of our position. If you have any questions about this testimony, please contact Jane Baird, Connecticut Children's Director of Government Relations, at 860-837-5557.

Sincerely,

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